Transition in Chronic Illness

Pain
Compiled by: Dr Debbie Kralik  RN, PhD  
Senior Research Fellow  
University of South Australia  
RDNS Research Unit  

Ms Kerry Telford BASW, Grad Dip Grief Counselling  
Researcher  
RDNS Research Unit.

Email: researchunit@rdns.org.au  
Website: http://www.rdns.org.au/research_unit

Titles in the 'Transition in chronic illness' booklet series  
1. Constant change: the shifting experience of illness  
2. Grief, loss and fear  
3. Shifts in self and identity  
4. Relationships  
5. Sexuality  
6. Fatigue  
7. Pain  
8. Interacting with others  
9. Our inner world  
10. Self-care  
11. Understanding Transition

Australian Research Council Discovery Grant DP0346092
© RDNS Research Unit – November 2005

This booklet is copyright. Apart from any fair dealing for the purposes of private study, research, criticism or review, as permitted under Australian copyright law, no part of this report may be reproduced or copied in any form, or scanned or stored in any type of information retrieval device or transmitted in any from or by any means, without the prior written permission of the author.

DISCLAIMER
This report is issued on the basis that:
- The information in it is intended as a guide only and should not replace the advice of a healthcare professional.
- You should rely on your own independent advice.
- No representation, warranty or undertaking is given or made as to the suitability or accuracy of the information for any specific purpose or the relevance, appropriateness, accuracy or reliability of any opinions, conclusions, recommendations or other information (all of which matters may change without notice) contained in this report.
- Save for any statutory liability that cannot be excluded, RDNS and its employees and agents disclaim and exclude to the maximum extent permitted by law all liability and responsibility (whether in negligence or otherwise) for any direct or indirect loss, damage or harm to personal property which may be suffered by any person relying upon this report.
- RDNS does not assume any obligation to update this report or correct any inaccuracy which may become apparent after it is issued.
- Provision of this report does not constitute endorsement by RDNS of any product or organisation referred to in it.
- All information contained in this report is gathered from research participants and academic literature that we believe to be reliable. However we cannot guarantee its accuracy and you should only rely on information and advices provided by your independent healthcare professional. We are passing on this information in good faith.
Contents

Pain That Is Ever Present 1
In The Presence Of Others 4
People That Matter 6
Caring For Others 8
Learning To Live With Pain 10
Our Message To You 12
Our Message To Health Workers 13
About Us 14
About The Booklets 15
About The Research Inquiry 15
What Are We Researching? 15
‘We who have pain on a daily basis have lost what others take for granted... the comfort and ease of a pain free body. I often try to remember how that felt.’

**Pain That Is Ever Present**

Pain, like fatigue, is a common ongoing symptom experienced by people who are learning to live with chronic illness. For some of us, pain and fatigue seem to be interrelated. Often pain may not respond to medication and is ever-present, with only the intensity varying. It becomes a part of life that cannot be ignored and has an impact on every aspect of our experience of life, including physical, psychological, intellectual, emotional, spiritual and social aspects. It can take many forms and is very difficult to describe and measure. Daily life becomes structured around keeping pain levels manageable, and parts of life that we once took for granted become pre-meditated. The sense of living a ‘normal’ life is lost.

People living with chronic pain may feel that they are different from others. Our independence may be threatened, along with a need to rely on others to do things that we are no longer able to manage. The way we interact socially may change due to the difficulty of engaging with a social situation when in pain. When we avoid social functions or no longer participate in activities that we once enjoyed, we can experience loneliness and isolation. When pain is ever-present we may experience a change in mood, such as irritability or grumpiness, and this might change the way we relate to those around us. It can alter the way we see and feel about ourselves, with resultant lowered confidence. Maintaining the balance between keeping pain at a tolerable level and enjoying our lives can feel like walking a tightrope. Nobody expects to live their life in pain and we are not prepared for it. When pain happens, the thought of enduring it for the rest of our life is overwhelming, as is evident in our conversations about pain.

**How does pain impact on your life?**

Pain has a large impact on my life having it present 24/7 between medium and high levels. It has restricted my activities to try to keep the levels as low as possible. Pain has a large effect on my physical, intellectual and emotional state. The physical [impact of pain] is obvious but the effect on my emotions has probably been greatest as it erodes away at your abilities to cope with normal life occurrences. It can take so much of your intellectual resources to just cope with the pain that it takes very little added load to overload you.

*Graham*

The pain I experience with Crohn's colitis is unpredictable and has different intensities. When I have a flare up, I experience the pain of a type of arthralgia or arthritis. This is a feature for some people of a flare up, and it is very hard to walk, get out of a chair and it saps my energy. I don't take
painkillers for this and usually cope by hiding it in front of others. Mostly and amazingly, people don’t notice, and if I explain why I am having trouble getting out of a chair I get blank stares. Other pain can be around the abdomen area and that can be quite painful and cause nausea and a general ill feeling. To date, I haven’t taken painkillers for this however, I know that some people with this disease experience horrific pain and double up, or are taken to hospital.

Di

Pain means that I am restricted in what I can do as the pain is usually in my hip or shoulder. I generally hurt all over most of the time anyway. Being touched physically can be quite painful at times but as I love hugs etc. from hubby and the children I put up with this. When my hip flares up it means that I can only walk very short distances before I have to rest for a long time. If it’s my shoulder then I can’t lift much and can hardly use my arm at all. When this happens I have to rely on hubby and the children to help out with things like hanging out the washing etc. It gets VERY frustrating at times.

Michelle

There is no short cut way of explaining my pain. What I type here barely covers the whole picture. If the pain is lower back, or upper and lower at once and in 10/10 flare-up mode, I can barely walk at all. I can’t straighten up and have to continually bend over especially if it is lower back pain. With intense pain I normally stay home as I just can’t be bothered to go out and I don’t normally buy much when in this sort of pain which hubby likes (lots of laughs!). When the pain is screaming at me and I can’t take anymore I generally take an Endone and this helps calm it down. Because I suffer from migraines, B12 deficiency, Fibromyalgia and Osteo-arthritis it is generally difficult for the GP to diagnose the symptoms. B12 affects the nerves and sometimes I can hardly move my left leg at all and it takes so much effort to do so especially at night when I have done too much during the day. The nerves from the brain are also affected and because it wasn’t diagnosed early enough I sometimes have symptoms of Parkinsons [disease] which is what they were testing me for first. With the Fibromyalgia there are a myriad of symptoms, with it being a form of soft-tissue or muscular rheumatism rather than arthritis of a joint. Sometimes one does question why one has to put up with so much pain? Battling pain daily takes a toll on being able to enjoy simple pleasures. Late nights are a thing of the past.

Julie

With my condition, pain is not really a problem (except for a recent episode of back trouble). However, there are often times when I just don’t feel right or I feel pretty tired. I have days when I just have to go to bed for a while after work. It is another negative aspect to chronic illness that makes finding positive things even more important.

Andrew
Pain is like a ‘silent companion’ - it never lets me out of its sight. That is to say, I’m in pain 100% of the day. Even though it severely limits what I physically do with my life, I try to not let it get to me psychologically. This is a big challenge and sometimes I win, sometimes I lose. Pain stops me being able to do simple things like sit in large groups and enjoy the company or sitting and doing nothing, whether it’s sitting on the porch, watching television or just laying in bed in the quiet of the morning.

Iolanda

It varies. Sometimes it is all encompassing and I find it necessary to withdraw - sometimes just from the outside world, sometimes completely, i.e. take to my bed for a while. It can prevent me from doing what I would like to.

Helen

Pain can make me very irritable, agitated and restless. My pain from chronic illness is usually headache. These are very much related to my blood sugar fluctuations. They vary in intensity and length. Sometimes I’m left quite incapacitated from a headache. Other times I barely recognise it is there. I find I have headaches up to 60% of the time, or on average about 4-5 days of a week. My longest ever headache lasted over three months without a break. The headaches are rarely just a few hours long. They tend to get worse during the course of a day, so that affects my energy levels. Sometimes I feel like I’m a complete waste of space by evening time. On mornings when I wake up with a headache I can usually expect the day to be a ‘write-off’. My cognitive processes are much slower with headache, and I experience a lot of brain fog. I also become very sensitive to noise and light. Artificial lighting becomes quite unbearable at times. Sometimes I get a lot of nausea, but thankfully have never vomited. Headaches also impact my social functioning, and I hate to be in crowds, or with more than just one or two people.

I occasionally experience pain/discomfort from gastro-oesophageal reflux, also resulting from blood sugar fluctuations. This pain is much more acute than headache and doesn’t impact my life on the levels that headaches do. At most, I feel uncomfortable with a stabbing pain through my chest, particularly on lying down - which can make sleeping a little difficult. It also affects my food and beverage choices while I am experiencing reflux. But that’s about it. And doesn’t last more than a day or two at a time.

Mari

Chained to my chair by
Chronic Fatigue – Iolanda

Pain is like a ‘silent companion’ - it never lets me out of its sight.
In The Presence Of Others

The experience of pain is usually not visible to others. Pain may be wreaking havoc within one's body however others, no matter how closely engaged, may not be aware of it. We learn that it is not socially acceptable to talk about being in pain. People are generally suspicious of pain and it is assumed that being in pain is not tolerable. Someone in pain is supposed to look different, with visible signs that they are suffering. When we talk about being in pain with no visible signs we risk not being believed and judgements being made about us. In the main, people may be uncomfortable hearing about pain and convey their discomfort in non-verbal ways. Effectively, people with pain are silenced.

We learn to protect ourselves by hiding pain and not disclosing it, or speaking about it in a superficial 'acceptable' manner which downplays the real experience. We suffer in silence. And yet we still have to carry out conversation and social activities. Seems like a near impossible ask. And sometimes it is. We all agree that enduring a social situation, struggling to engage in conversation and be happy or positive is almost impossible when we are experiencing high levels of pain. Most of us avoid or leave social situations. We have developed some ‘tried and true’ excuses such as ‘I’m not feeling well’ or ‘I’ve had a long day’. It’s a part of looking after ourselves to retreat, and we do not give ourselves a hard time over it, even though we may resent having to leave.

There is a general acceptance among us that other people do not want to hear about pain and so if we do not have the option to leave the situation (e.g. at work), then we ‘soldier on’. In an ideal world we would be able to talk about pain without negative reactions, but the reality is that disclosing pain leaves us vulnerable to others’ judgements. Protecting ourselves in these situations becomes a priority. This is evident as we discuss how we each manage that.

**What has been your experience of coping with pain in the presence of others?**

People are conditioned to see pain as something physically obvious like having a bandage showing. I have tended to not try to tell anyone unless I have to, as I have always received blank stares and comments like “you look alright”.

_Graham_

I hide it if possible; I make light of it and just say ‘oh I feel really stiff today’; I explain it but usually have a blank response from others; or if it is in the abdomen area I would be at home feeling too ill for company.

_Di_

I just tell people. Most of my family now understand that if I’m quiet it’s because I am either really fatigued or in a lot of pain. With hubby and the children I just tell them that I’m in a lot of pain or I have my migraine and need to just sit/lie down and rest for a while. Most of the time they are pretty
understanding and the children joke [good naturedly] about my hip/shoulder giving out on me. Mostly I just try to soldier on and put on a brave face. If I am feeling particularly bad I will excuse myself and leave rather than have them witness my pain or drawing attention to myself.

Michelle

Depends on the level on pain/discomfort. When you are with other people though it can be an extra effort to appear positive to them. Particularly in a social setting, people prefer not to be around unhappy people, but they do also want to help us. So sometimes, try as we must to be positive it can be better for others for us to go home. Staying home can help ease the pain, but adds to our sense of isolation. Being in pain while in a social setting can be a no-win situation.

Andrew

If I were meeting a stranger they probably wouldn’t know the pain that I’m experiencing from my behaviour (or any of the other medical problems that I suffer for that matter). But since most people know that I’m unwell, after many years of experience I’ve come down to a few coping mechanisms. I generally try staying away from larger groups of people, which is unfortunate because it stops me doing some family things. In some situations, like the writer’s group that I go to, I try to do other things [distractions from pain] while I sit there (like sewing). But this is only really possible in a few situations and if I have the energy. Otherwise I leave early.

Iolanda

I find it very isolating. If I am in bad pain it is as if I am apart from others, behind glass or something. There was a Panadeine advertisement a few years ago which demonstrated this very well. The person with pain was at one end of a very long table and the rest of the group was away down the other end. That’s just how I feel at times. Pain also makes it hard for me to talk to others. It is as if it has taken all my energy to go out and I have none left over to use talking etc.

Helen

Soldier on. Sometimes I might say something about my pain if I feel it’s contributing to the way I interact with others. Having said that, I don’t think I’ve ever mentioned the experience of pain to any of my clients during consultation. I’ve never viewed that kind of transparency as being professional. So it really is a case of ‘soldier on’.

Mari
People That Matter

Chronic pain is a place where, gradually, almost without noticing, people may find themselves alone. Chronic pain penetrates the sense of self, it lives deeply within people, often unseen to the outside world.

While it is difficult to describe pain, we think that it is important that the people who matter in our lives have some level of understanding about our experience of pain. This helps them to be supportive and avoids misinterpretation of pain-related behaviour. In order to achieve this we need to talk to them about it. We are aware that we do not want to burden them and that they may find it distressing to hear about someone they love or care for being in pain. Past experience teaches us to proceed carefully and to be selective about what we say. Others may be frightened by pain, and so any discussion of pain needs to reassure that the pain will subside and will not cause harm. We have found it useful to let them know what level of pain we have and to focus on what our needs are. We do not dwell on the pain, but simply communicate that it is present. There is usually an unspoken understanding that builds up over time about what that means and what we need from them. Generally, seeing loved ones in pain raises feelings of helplessness in the face of suffering. Knowing that there are things that can be done to support the person in pain relieves the sense of helplessness.

We are selective about who we talk to about pain. It is likely to be immediate family, but it also could be close friends or work colleagues. Those decisions are made on the basis of how useful it is for them to know. Others learn by just being around us and sharing in some of the trials of chronic illness. Seeing someone you love or care for in pain gives perspective to one's experience of life and raises awareness of and compassion about the suffering of others. We can take responsibility for communicating about pain in a manner that leaves the other person reassured and safe, as we discuss here.

What have you found helpful in communicating to loved ones about pain?

I have found creating similes the easiest to convey my levels of pain e.g. a hot steel spike is being shoved down my legs, or someone has just hit my fingers with a hammer, are quickest.

*Graham*

I explain that I've no energy because the pain is linked to another feature, that of fatigue. I explain I can't get up or will be slow, I might need to lie down for a while or sit quietly. This then can be understood however it frightens loved ones who are not sure of what might happen. So the need to have someone understand and be kind is mixed in with having to reassure that it doesn't mean imminent death, it is just uncomfortable and can some times be agonizing. Kindness, sympathy and help with medications, cooking or the like is what is needed and that is the message I try to get across.

*Di*
I have found that its best to just explain exactly how I am feeling and that I won't be able to do anything much for awhile, for even a couple of days. As my husband also has a chronic condition he understands this as well. The children have learned to live with it and often find the humour in a situation. With my husband and parents I usually try to explain to them that it [the pain] is often relentless. Others who suffer from pain after an accident often have pain for awhile and get over it, others don't and it becomes chronic. Those close to me know that I have suffered from chronic ear operations in the past and knew what pain I had with them and also knew that I was brave. I didn't complain I just did what I had to until the next operation. They saw that I didn't complain unnecessarily, that I got over my hysterectomy in a hurry even though they could see I was in pain. They used to see me in difficulties before I was diagnosed with the B12 [deficiency] that is before I had my injections to keep me from being unable to walk at times, to co-ordinate, to think, shaking hands etc. but they could also see that I coped with it all. With my shoulder pain and back pain they know it is harder because I have explained how it affects me. They also know that I still get on with it. So when I say I am in bad pain they know.

Michelle

It is important not to come across as ‘whingeing’ about the pain, but rather to come out with a full story: problem and solution. ‘I am in a lot of pain at the moment so I need to have some tablets and lie down for a while’. This helps other people to deal with it as well - they are often concerned, so if you can communicate to them what you need it helps them.

Andrew

I once tried to get my family to experience the pain for themselves - so I wrapped a tens machine around them at a certain setting and they experienced in one small part of their body what I experience all over my body. Otherwise, with others I’ve used descriptive words like burning, tearing, stinging etc.. And my boyfriend at the time didn’t listen - I’d been experiencing pain for a while and when I told him I was going to the doctor for it he was surprised since he didn’t know I was suffering. Although fatigue stopped me doing more than the pain, he wasn’t interested in listening to anything anyway. We’re not together anymore so it isn’t an issue.

Iolanda

I tell my loved ones when I am in bad pain so that they can at least understand why I might be grouchy, withdrawn or vague. I try not to dwell on it but it is necessary when the pain is really bad. Having another family member with chronic pain also helps. He and I often discuss coping mechanisms, how it affects us and those we live with and generally give each other support and
encouragement. Having a member of the extended family who understands this is quite helpful too. Knowing that the rest of the family accepts my pain and that they know I am doing the best I can is also a big help. It is hard for the “healthy” ones who often need to adapt their lives to fit in with my pain. My husband is used to spending evenings alone (as I often need to go to bed very early); to going out alone; or to being quiet while I sleep off a migraine.

Helen

My communication to loved ones about my pain is to tell them when I am experiencing pain, and at what intensity (if needs be...). They have learned to know how headaches affect my ‘output’ and adjust their expectations accordingly. People who know me well also seem to recognise my headaches just by identifying it through looking at my eyes. My mum and workmates are particularly skilled at this now.

Mari

Caring For Ourselves

Just as we find a way to live with other ongoing symptoms, we also find a way to live with pain. From our experience, this evolves from the learning process that is taking place every moment we live with chronic illness. We problem-solve pain as part of everyday life as we learn what helps and what does not.

A significant part of that learning has been having the opportunity to hear and talk with other people about their experience and management of pain. Hearing other people’s experiences affirms our strengths and validates our experience of pain. We do not feel so alone with pain when we are in contact with others in similar situations. Learning what the particular triggers are for pain assists in knowing what to avoid. Certainly we find that lifestyle changes are important, such as ensuring that there are ample opportunities to rest and relax. Pain seems to be worse when we are stressed or exhausted, so we plan our life to avoid them wherever possible. We find living a quieter life and having enjoyable distractions creates a context in which we are better able to manage pain. For some this has meant leaving employment and opting for a less stressful life. Others find it is important to build in regular bodywork such as gentle exercise, hydrotherapy, physiotherapy or massage. We might turn to complimentary or alternative options such as aromatherapy or non-chemical treatments. Perhaps using psychological techniques such as imagery or positive self-talk will assist the pain to be less intrusive. It is worth giving these strategies a try because they can give back a sense of control.

We acknowledge that even with the above strategies we may still have days of intense pain where nothing seems to work. Managing those days so that we are not overwhelmed by it is a challenge. We find that we tend to focus inward and do what we need to feel even a marginal improvement or, at the very least, as comfortable as we can be. Sometimes we will have a day in bed with our body at complete rest. There are a range of things that we can do in order to nurture ourselves and be comfortable, such as keeping warm, lying in a bath, using a hot water bottle on the painful areas, listening to favourite music or having a massage. On these days it is important to remember that there have been many times in the past when we have felt pain and that it always lessens. Remembering the last time that you had intense pain and the way it reduced or resolved is helpful.
We now discuss what we have found works for each of us.

**What have you found helpful in enabling you live with pain?**

I try to keep myself as active, both physically and mentally as much as possible, albeit slowly. I am unable to concentrate, sit, stand etc. for any length of time so I tend to have a few different, interesting things to occupy myself.

*Graham*

Resting, taking life quietly, sometimes physiotherapy and massage helps. I can sit down and do nothing because I no longer have to travel to work through peak hour traffic to a full time job where I have to perform.

*Di*

Most of my pain is not treated well with medication. Sometimes having a super hot shower helps to take away the aching for a while. Lying down also helps relieve the aching a small amount. Mostly you just have to put up with it and try to distract yourself with something else.

*Julie*

I either meditate or listen to soothing music. I try to think of a peaceful place a calm place, running water, I use heat pads or have a spa. Everybody is different, different things work at different times, so try different things. Rest/relaxation can help a lot as stress makes everything tense - so try relaxing in a bath for a while. Also don’t underestimate the value of aromatherapy - I think it does have some effect, even if not directly, the act of using it helps tell YOU to relax. Look at what sort of pain it is and what may be the trigger. I found that a major cause of my back pain was from sleeping on my side. You may find that a Chiropractor or Physiotherapist or even a good masseur can help.

*Andrew*

Five main things are invaluable in helping me to live with the pain:

- to plan my activities so I’m not overdoing it.
- online support groups are invaluable. Absolutely invaluable. Knowing that I’m not alone in my struggles is a benefit that I experience 24 hours a day, each and every day, and one that I wouldn’t be able to get from a physical support group either. I know I wouldn’t have coped with my situation even half as well as I have without access to the internet and these support groups.
- The existence of voluntary euthanasia has removed any fears I have of aging and more pain.
- distraction. I try to keep mentally busy so I’m not focussed on the pain.
- having a hobby or passion is invaluable in having something to look forward to and something that feeds your soul. Besides the computer and internet, I’m also a collector and this is something that I can enjoy throughout the day.

*Iolanda*

Be kind to myself on ‘pain-full’ days.
Relaxation exercises, gentle exercise, self-talk [ie. trying to recall the times when the pain was better, remembering that the pain isn't always this bad, that it won't kill me etc.]; non-medication treatment, e.g. I wear a splint on my teeth to adjust my bite and lessen the chronic pain in my jaw.

_Helen_

Sometimes I rely on medication although I need to take it early on if it’s going to make even the slightest dent in relieving pain. Rest and aromatherapy seem to work best for my headaches. I avoid excess reading, computer work, television viewing, bright lights, crowds, noisy places etc. If the headache is ‘not too bad’, distraction works well (I believe there may be a technical term for that - diversional therapy, perhaps?). Some of my headaches seem to be more susceptible to becoming ‘worse’ than others, so I try to identify the ones that have that propensity and avoid things that aggravate my headaches (including those that I’ve mentioned plus alcohol and a high carbohydrate intake).

I’ve been having therapeutic massage and chiropractic treatment for managing sciatica pain. Generally maintaining flexibility and a good posture also helps, so I try to do some yoga, pilates and swimming to keep my back healthy.

_Mari_

**Learning To Live With Pain**

Some things stand out to us as being ‘pearls of wisdom’ in learning to live with pain. We thought it might be helpful to share them. As we have said, we live in a social context that is largely unsupportive of the experience of pain and it is easy to feel alone with it. When we feel like this we can become overwhelmed and consumed with pain. Our strongest message is to try to avoid states of desperation and panic by being in contact with a supportive group or network of people who live with pain. This will provide a place where pain stories can be shared and understood. Coping skills are developed as people share each other’s wisdom about what helps. Connecting with others who understand about pain creates a place where it is safe to talk about pain and reduces the feeling of being alone. The internet makes this accessible, even on days when pain is high and regardless of location.

Chronic pain destroys a person’s ‘taken-for-granted’ assumptions about the world. We who have pain on a daily basis have lost what others take for granted ... the comfort and ease of a pain free body. I often try to remember how that felt. Ultimately, pain introduces people to an unsettling world where time has stopped. The time before pain intervened in their lives can be almost inconceivable, or recedes in a person’s memory like a faded dream. For people with chronic pain, suffering becomes interspersed with enduring.

The support of others is significant in managing pain. Knowing that there are others who care about your experience of pain and want to do whatever they can to support you eases the sense of aloneness and averts desperation. If it is not possible to have the support of family, then maybe a
close friend can help. If not family or friends, then maybe a health care worker. It is important to know that someone else is concerned about and supportive of our experience of pain.

Understanding the reasons for pain, where possible, is important to some of us as is accepting it as part of life. Mostly we hear about short term pain and are not prepared when pain does not disappear. And so begins a long journey of integrating the experience of pain as part of life and learning ways to live the best life possible despite pain. Be mindful of enjoying each moment of days when pain is minimal or absent. If the pain is high, nurture and indulge yourself to achieve a level of comfort. Take heart in the knowledge that pain changes and will usually lessen to a point where life can be enjoyed again.

What has been important for you when learning to live with pain?

The unconditional love and support of my wife has kept me wanting to learn to live with the pain.

Graham

Information about my illness is important so that I know why I have pain rather than panic not knowing what it could be. Knowledge gained from authentic web sites that have items which have bulletin boards or the like showing that other patients with the same disease as mine, feel the same way as I do. This is helpful because I then know I am not the only one. I know I can ring my specialist if the pain is unbearable or unusual or overwhelmingly sudden and having supportive partner is helpful too.

Di

Accepting that it's going to be a constant in my life. Accepting that there really isn't much that I can do about it and that I just have to put up with it.

I know there are others worse off than me and that helps. I think positive. I have my faith without that I wouldn't be here now. Those closest to me know what I am going through and to me that is important when having to live with pain.

Julie

Pain for me is not a significant problem, feeling off colour at times is. The important thing is to work out what works for you to help with the pain. With a chronic illness, we have to deal with a number of negative influences in our life, which other people don't. This makes it more important for us to find positive things to balance them.

Andrew
A supportive family environment is probably the most important thing. My mother is absolutely great - she expects very little from me so this reduces the increased fatigue and pain levels that I’d otherwise experience. And being part of online support groups is invaluable - it helps me not to feel so alone and feeds my confidence.

Iolanda

Understanding the source of the pain [i.e. where it comes from as opposed to why I have it]; knowing that I am not alone in my pain; support groups especially this one. Having a supportive environment also helps. If you are basically content the pain is lessened a bit.

Helen

Pain (most commonly headache) is an inevitable part of my illness package. Enjoy and make the most of the pain-free days. Be kind to myself on ‘pain-full’ days.

Mari

Our Message To You

We can become preoccupied in finding and providing quick relief from aches, pain, grief or discomfort. The reality is that there are no quick fixes, and pain generally cannot be completely removed or controlled. Some pain is necessary and serves a purpose as a messenger. Then there is the insidious kind of pain that seems to have no message or purpose. The experience of ever-present pain can spiral and entwine with other symptoms, particularly fatigue. When chronic pain and fatigue become entwined, powerlessness and depression may be close behind.

Learning to live with pain is a difficult process and the recipe is not always the same for everyone. We can learn to live with pain and listen to it rather than always trying to medicate it away. To do this requires a significant commitment to ourselves and a willingness to confront and challenge our prior understandings and values. We learn over time to give ourselves permission to feel, without labels, judgments or time limits. We let go of society’s expectations and listen to our internal wisdom.

At times it may be hard for us to hear the messages carried in our pain, or to appreciate them, because the pain is overwhelming. There may be setbacks into our old ways of thinking and we may not be able to adapt and find meaning for a while. Sometimes we may feel angry at our fate. This is all part of the process of learning to live with illness and it needs to be felt and respected.
We encourage you to reach out for help, advice and understanding. Consider a variety of strategies that may complement the more traditional pain therapies. Some examples are aromatherapy, massage, imagery and disassociation. Seek qualified therapists or health workers for assistance with diverse pain strategies. Books, media and Internet resources can be important for those of us seeking validation and knowledge from the experiences of others. Validation and affirmation from others can chip away at the sense of aloneness that often accompanies chronic pain, as those of us enduring chronic pain can be reminded by others of our unique strengths and qualities. Reflecting on past pain experiences can pave a smoother way for people learning strategies for self-care that may be tried in the future.

Our Message To Health Workers

We want you to acknowledge our experiences of pain. We want you to go further than simply to focus on the symptoms and progression of disease, but to also incorporate the impact of the illness and the meaning within our lives. Respect for the context of our lives becomes central to the relationship we have with you.

The person living with chronic pain belongs to a world that no one else can entirely share or comprehend. Know that pain is difficult to measure and impossible to visualise. Health workers use various scales, asking people to rate their discomfort from 0 to 10, or from blue to red, signifying a range from nearly pain-free to the worst pain imaginable. But a 10 is sometimes not an adequate measure when the pain is screaming. We may experience first hand the failure of words in the face of prolonged suffering with pain. When trying to describe pain to a health worker, our language runs dry as the experience of pain escapes articulation.

As chronic pain consumes people’s lives, anxiety and depression may close in. Some people with chronic pain benefit from good health care and effective medication that can keep help to keep despair at bay. All too frequently, people have to settle for a lot less. Many people, suspected of faking symptoms to get drugs or time off work, spend years convincing health workers that their troubles are real. People with chronic pain can visit multiple health workers, their hopelessness building as they go. In the worst scenarios, lives fall apart.

Enduring unrelenting physical pain is likely to cause emotional distress as one struggles to cope with feelings such as profound loss, grief and anger that is associated with diminished abilities and changes in lifestyle or identity. In forming a new identity that includes living with pain, one may ask questions such as “Why me? And “What is the purpose of my life now?” Health workers can assist us to take a painful experience and make meaning out of it by helping to reflect on the experience, think about what happened and what helped and then to explore our actions and responses to that painful situation. In this we learn together. In spite of the challenges that illness brings to our lives, it may also help us to change, grow and learn.
About Us

We are men and women who live with chronic illness. Our ages, sexuality, backgrounds and economic situations are diverse and these all impact on the way we experience illness. We are participants in an Australian research project that connects people living with long term illness through the Internet. Talking with each other on the Internet facilitates an opportunity to discuss issues related to our experience. We came together through being involved in a research project. Over time we have got to know each other through our email conversations. We feel strongly connected to a network of caring and support that carries us through the hard times and enables us to celebrate each other’s good times. Knowing that we can always tap into understanding and support of others who live with chronic conditions is important in our approach to making sense of and managing illness.

There has been a lot of discussion about chronic illness self management promoted by health care professionals. Yet it has been estimated that between 95 percent and 99 percent of chronic illness care is given by the person who has the illness. In other words, we look after ourselves. On a day-to-day basis, we are in charge of our own health and the daily decisions we make impact upon our quality of life.

We all have something in common: we live with a chronic illness. A chronic illness is one that persists over time without an easily definable beginning, middle and end. While the symptoms that accompany a chronic illness can usually be alleviated to some extent, the illness itself is not curable. What we share is that illness was an unexpected intrusion into our lives.

Living with chronic illness brings many life issues to the fore. One of the primary experiences for us has been the realisation that our lives have changed, often permanently. Illness has disrupted our future plans. It has troubled our partners, family and friends when they realise the way in which illness has intruded on our collective lives. However, we are learning to deal with the many changes that the illness has bought to our lives.

Over time we have come to realise that although there are differences among us, there are experiences in common too. Some of these experiences such as pain or isolation have made us feel alone in the past. We have learnt the value of hearing the ideas and perspectives of other people in similar situations, so we have worked together to develop this series of ten booklets. Not all of the people in this project have been able to contribute to the booklets. Rather, a group of eleven people has been consistently involved.
About The Booklets

We decided to share our experiences in a series of eleven booklets. The purpose of these booklets is to share some of our conversations about many interesting and difficult aspects of living with illness. Our conversations have been a safe place where we can seek understanding and support as we tackle the issues that confront us physically, emotionally, socially and spiritually. We are supporting each other by sharing information, emotional comfort and friendship. In these booklets we share our discussions.

The booklets are set out in question and answer format, and are intended to connect you with our voices about our experience of living with long term illness. There are no right or wrong answers to these questions. Our answers reflect our current thinking and understanding about what it means to live with long term illness. Maybe you will find some experiences and ideas that are familiar to you or have meaning in the context of your life. We acknowledge that challenges are part of life and fall within the experience of all human beings. Given this, our experiences may also be helpful to people living without illness.

About The Research Inquiry

A three year research grant (2003-2006) from the Australian Research Council (ARC) was awarded to our research team. This was a collaborative project between The University of South Australia and the Research Unit, Royal District Nursing Service. The investigators are Professor Tina Koch, Dr Debbie Kralik and Dr Kay Price. Project Management Members are Kerry Telford, Professor Jim Warren, Gino Pignone and Natalie Howard.

What Are We Researching?

The main thrust of the research program has been to understand the ways that people make transitions or learn to live well with chronic illness. We are interested in ways that people can learn to incorporate the consequences of chronic illness into their lives and move on. How people learn to move on or make transitions is important to understand, and so this project aims to describe this transition.